

# Food Sensitive Study: Wave Two Survey

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## Executive Summary

### Introduction

Food hypersensitivities (FH) include food allergy, food intolerance and coeliac disease. Food allergy and coeliac disease involve an immune mediated reaction to certain foods; food intolerance is caused by a non-immune mediated reaction (such as an enzymatic or pharmacological effect). Each of these FHs result in unpleasant symptoms if the food is eaten in sufficient quantity, with food allergic reactions sometimes resulting in life-threatening symptoms.

Management of FH by an individual or members of their family therefore involves constant vigilance and risk assessment to determine if a food is safe to eat. Research over the last twenty years has demonstrated that this burden, along with the unpredictable nature of FH reactions, has an impact on quality of life (QoL). QoL encompasses our emotions, physical health, the environment we live in, our social networks and day-to-day activities. FH has been shown to have an impact on many of these areas, however there are still research gaps. In particular, many studies focus on children, adolescents or parents rather than the adult population and little is known about those with food intolerances. In order to make a comprehensive characterisation and evaluation of the burden caused by living with FH, the day-to-day management of FH and associated inconveniences, the FSA has commissioned this project, led by Aston University. The project is called the FoodSensitive study and this report relates to findings for workstream one, a survey to assess the impact of FH on QoL. This survey was carried out in two waves, one year apart. This report covers the second wave and a comparison of wave one and two for those participants who completed both waves.

### Research aim

The aim of this survey was to characterise the management of FH of individuals living in the UK and evaluate the resultant impact on their QoL. A further aim was to compare management of FH on individuals who completed the survey at two time points, one year apart, to explore any changes in the impact of FH on these individuals.

## Methods

### Design

This was a cross-sectional online survey. It was administered one year after the previous survey and so is also a part longitudinal design for participants who completed both waves. This report provides the findings for the second of these two waves and a comparison of data from wave 1 and wave 2 for those participants who completed both waves. Key data collected included:

- detailed information on foods, symptoms, diagnosis, medication and hospitalisation
- experiences when eating out
- general and FH specific quality of life.

The data was collected between 10th October 2021 and 14th December 2021. During this time people living in the UK experienced some restrictions on day-to-day living, including eating out, due to the Covid-19 pandemic. This should be considered when considering the results.

## **Participants**

Participants were adults with FH, parents of children with FH (aged 0 to 17 years) and children (aged 8 to 17 years) with FH, living in the UK. FH was defined as experiencing a bad or unpleasant physical reaction after consuming food. An opportunity sample (anyone who saw the study advert and was eligible to take part) was recruited through advertising via patient organisations: Allergy UK, the Anaphylaxis Campaign, the Natasha Allergy Research Foundation and Coeliac UK. The survey was also advertised on Twitter and had a study webpage with links to the surveys on the FSA site. Participants were also recruited through online survey panels via Qualtrics. In addition, participants from wave one who stated they were happy to be contacted again about the survey were sent an email with the study invite and a link to the survey.

## **Measures**

All measures used in wave 1 were re-used for wave 2. There were some minor amendments to questions about the day-to-day management of FH. Some questions about experiencing reactions in front of others were removed as the FSA had included them in their Food and You 2 survey. Other questions were added, such as how many reactions participants had experienced in the last year and where.

Participants first completed a questionnaire developed by the project team to collect demographic data and information about FH and eating out. When asking about foods, participants were asked to first provide a list of all foods they (or their child) reacted to, and then provide more detailed information on up to three of those foods that they considered had a big impact on their lives. For each of these foods they were asked to say whether they thought their reaction was a food allergy, food intolerance or coeliac disease. Their response to this question for the first food they reported details on was used to direct them to the appropriate quality of life scale. They were also asked to say whether they thought the FH was mild, moderate or severe.

In order to measure quality of life, existing validated measures were used. In order to measure quality of life that was specific to FH we used food allergy, food intolerance and coeliac disease quality of life scales. We also measured general quality of life using the EQ-5D. This scale measures quality of life in general domains such as usual activities, pain, mobility, and anxiety. All FH specific and general quality of life scales were age-appropriate, and parents completed proxy versions for their children.

## **Data Analysis**

Participants were put into the following sub-groups for analysis:

1. Respondents with food allergy only
2. Respondents with food intolerance only

3. Respondents with coeliac disease only
4. Respondents with multiple hypersensitivities which included any two (or all three) of allergy, intolerance and coeliac disease.

Descriptive information is provided for all survey questions in the form of text, tables and graphs where appropriate. Comparisons across mean scores for groups were conducted using ANOVAs, which provide an overall F value to tell you if there is a significant difference. The effect size ( $\eta^2$ ) was reported for all ANOVAs. Pearson's correlations were used to examine relationships between pairs of continuous variables. Correlations are used to see if two sets of data are related in some way, so for example to see if higher scores in a variable is related to higher or lower scores in another variable. Where group sizes were large enough, regression analysis was conducted to see what variables might predict QoL.

For the QoL analysis, the following comparisons were made for each group where appropriate:

- between clinically diagnosed and self-diagnosed conditions
- by gender
- by age
- by number of foods/allergens reported
- self-reported severity

For participants who had completed wave 1 and wave 2, answers to survey questions were compared for changes over time where there were sufficient numbers in each group.

## Results

A total of 1,065 adults with FH, 750 parents of children with FH, and 349 children with FH completed the survey for wave 2 and were included in this report. Of these 313 adults, 77 parents and 15 children with FH had also completed wave 1. Those reporting 'other' and 'don't know' regarding the type of FH they had were excluded from the statistical analysis as we focused on the specific sub-groups listed above, however they were included when reporting descriptive information for the whole sample. For comparisons between wave 1 and wave 2, only answers from adults and parents were compared as numbers were too small to compare results for children.

## Key findings for adults

### Sample characteristics

- overall, 1,065 adults took part in wave 2: 323 with food allergy; 330 with food intolerance; 217 with coeliac disease; 131 with multiple hypersensitivities
- most adult respondents were female (76%); the mean age of respondents was 51 years old, with a minimum of 18 years and a maximum of 86 years
- adults reported detailed information on 1,549 foods which caused a bad or unpleasant physical reaction (please note this is not separate types of food but the number of foods reported in total by adults). The most common food reported was cereals containing gluten (n = 403; 26%), followed by other foods (n = 222; 14%) and milk (n = 178; 11%).

### Eating out

- over half (66%) of adult respondents felt comfortable in asking staff for information when eating out because of a concern about experiencing a bad or unpleasant physical reaction to food

- over half (60%) of adult respondents felt confident that written information provided by the venue when eating out allows them to identify foods that cause a reaction. Adults were less confident in information provided verbally by staff (52% reported being very or fairly confident)
- a quarter of adult respondents (25%) reported that they had been refused service when eating out because of their FH, and around one in ten (14%) had previously been asked to sign a disclaimer when eating out
- 40% of respondents reported at least one reaction to food in the last 12 months to and most of these reactions were experienced at home (62%)

## Quality of life

- the average scores captured on the FH specific quality of life scales indicated that adult respondents felt that their FH affected their quality of life 'moderately' to 'quite a bit'
- adults with FH who reacted to more than one food reported significantly poorer FH specific quality of life than those who only reacted to one food
- adults who self-reported mild or moderate FH reactions reported significantly better FH specific quality of life than those who reported severe reactions
- adults with food intolerance or multiple FHs reported lower generic quality of life (scored using the EQ-5D-5L) than adults with food allergy or coeliac disease
- compared to the UK population distributions for the EQ-5D-5L, significantly less adults reported the 'best' quality of life, but significantly more reported 'moderate' quality of life across all sub-domains
- eating out more frequently was significantly related to better FH specific quality of life
- checking information more frequently, at most stages of eating out, was significantly related to poorer FH specific quality of life
- how comfortable participants were in asking staff for information when eating out, and how confident they were in the written and verbal information provided when eating out was significantly related to better FH specific quality of life.
- reacting to food in a product or dish served despite checking available allergen information was significantly related to poorer FH specific QoL
- in regression analyses, a more severe reaction (self-reported as mild, moderate or severe), greater number of foods reacted to, greater frequency of checking information, greater frequency of asking staff for information and greater number of reactions in the last 12 months significantly predicted poorer FH specific QoL.

## Comparisons between adults in Wave 1 and Wave 2

- a total of 313 adults completed the survey at both time points
- there were no significant differences between wave 1 and 2 in frequency of eating out, frequency of checking information, feeling comfortable or confidence in verbal information provided about allergens
- adults in wave 2 were significantly less confident in written information provided about allergens than in wave 1
- there were no significant differences between wave 1 and 2 for food allergy specific QoL
- those with food intolerance or coeliac disease reported significantly better FH specific QoL in wave 2 compared to wave 1
- however, generic QoL as measured by the EQ5D visual analogue scale, was significantly poorer in wave 2 compared to wave 1

## Key findings for parents

### Sample characteristics

- overall, 750 parents took part in wave 2 (reporting on n = 933 children): 399 parents of children with food allergy; 176 with food intolerance; 21 with coeliac disease; 134 with multiple hypersensitivities
- 78% of parent respondents were female; the mean age of respondents was 37.1 years (range 18 to 62 years)
- 57% of the children were male; the average age of the children was 7.7 years (range 0 to 17 years)
- parents reported detailed information on 1,523 foods their children reacted to (please note this is not separate types of food but the number of foods reported in total by parents). Tree nuts (n = 298; 20%), milk (n = 296; 19%), eggs (n = 215; 14%) and peanuts (n = 142; 9%) were the most frequently reported foods

## Eating out

- almost three quarters (72%) of parent respondents felt comfortable in asking staff for information when eating out, because of a concern about their child experiencing a bad or unpleasant physical reaction to food
- two thirds (65%) of parents felt confident that written information provided when eating out allows them to identify foods that will cause their child a reaction
- slightly fewer parents (55%) were confident in information provided verbally by staff
- a third of parents (34%) reported they had been refused service when eating out because of their child's FH, and 23% reported they had been asked to sign a disclaimer when eating out because of their child's reactions to food
- the majority of parents (76%) reported their child had experienced at least one reaction to food in the last 12 months and most of these reactions (52%) were experienced at home, followed by at school (14%)

## Quality of life

- the average score on the FH specific quality of life scales indicated that parents felt that their child's FH affected their child's quality of life 'quite a bit' or 'very much'
- there were no differences in FH specific quality of life based on age or gender of the child
- parents who self-reported that their child experienced mild or moderate reactions reported significantly better FH specific quality of life than those with children who reported experiencing severe reactions
- parents of children with multiple FHs reported the poorest generic quality of life for their child (scored using the EQ-5D-3L), followed by coeliac disease, food intolerance and then food allergy
- parents of children with FH reported their children had better quality of life for mobility and usual activities compared to parent-reported quality of life for pain and anxiety on the generic QoL scale
- in regression analyses, a more severe reaction (self-reported as mild, moderate or severe) significantly predicted poorer FH specific QoL for teens (13-17 years)

## Comparison between parents in Wave 1 and Wave 2

- a total of 77 parents completed the survey at both time points
- parents reported they ate out significantly more often at wave 2 compared to wave one (less than once a month compared to around once a month)
- there were no significant differences between wave 1 and 2 in frequency of checking information, feeling comfortable or confident in verbal or written information provided about allergens
- parent-reported generic QoL (as measured by the EQ5D visual analogue scale), for children was significantly better in wave 1 compared to wave 2

# Key findings for children

## Sample characteristics

- overall, 349 children took part: 141 with food allergy; 139 with food intolerance; 29 with coeliac disease; 21 with multiple hypersensitivities
- just over half (52%) of child respondents were male; the average age of the children was 12.6 years (range of 8 to 17 years)
- the children reported detailed information on 440 foods they reacted to (please note this is not separate types of food but the number of foods reported in total by children). The food most commonly reported was milk (18%)

## Eating out

- when eating out and before ordering food, just under half of child respondents reviewed available information always or most of the time (49%)
- just over half (56%) of children felt comfortable asking a member of staff for information about the food when eating out, because of a concern about experiencing a bad or unpleasant physical reaction
- almost two thirds (63%) of children felt confident that the written information provided when eating out that allows them to identify foods that cause them a bad or unpleasant physical reaction. A slightly lower proportion of children were confident in the information provided verbally by staff when eating out (59%)
- around a fifth (22%) of children reported they had previously been refused service when eating out because of their FH
- 79% of children stated they had had a reaction in the last 12 months and the majority of the reactions happened when they were at home (58%)

## Quality of life

- the average score on the FH specific quality of life scales indicated that children felt that their FH affected their quality of life 'moderately' to 'quite a bit'
- there were no differences in FH specific quality of life based on age or gender
- children with self-reported mild or moderate reactions reported better FH specific quality of life than those with severe reactions
- 8-12 year-olds with food allergy or intolerance had similar scores on the EQ-5D-3L regarding generic quality of life, with those with multiple FHs scoring lowest, and all children with FH scored worse for pain/discomfort and anxiety/depression than they scored for usual activities or mobility
- 13-17 year-olds with food allergy had better scores on the EQ-5D-5L regarding quality of life than those with intolerance and coeliac disease, and all respondents in this age group scored worse for pain/discomfort and anxiety/depression than they scored for usual activities or mobility
- generic QoL as measured by the EQ5D visual analogue scale, was significantly poorer in wave 2 compared to wave 1.
- in regression analyses, higher frequency of checking available information before choosing where to eat out significantly predicted poorer FH specific QoL for children aged 8-12 years with food allergy or intolerance; severity of FH significantly predicted poorer FH specific QoL for teens aged 13-17 years with food allergy
- no comparisons between wave 1 and wave 2 were made for children as not enough children completed both waves

## Conclusions

The second wave of this UK based survey has provided further insights into the impact of FH on day-to-day activities and quality of life of adults and children. Similar to wave 1, a wide variety of foods causing unpleasant symptoms were reported, with foods containing gluten, milk, tree nuts and peanuts reported most often. Similarly, participants reported a range of symptoms, from gastrointestinal, skin reactions, breathing difficulties, swelling and anaphylaxis.

## **Eating out**

The findings from the wave 2 cohort are very similar to the wave 1 cohort regarding eating out.

Similar to wave 1, adults and parents reported being more confident in written information provided by staff when eating out, compared to information provided verbally. However for those adults who completed both waves, confidence in written information was less in wave 2 compared to wave 1. It is unclear why this difference might be. Legislation for pre-packed food for direct sale came into law in October 2021 when the second survey was launched, meaning that full ingredient labelling was needed, but this may not have had much impact on consumers in the short time the surveys were live. The worldwide Covid pandemic and the UK leaving the EU disrupted supply chains and substitutions to foods may have increased the use of precautionary allergen labelling, which may have contributed to this.

Similar proportions of adults, children with FH and parents of children with FH reported they felt comfortable asking a member of staff for information because of a concern about experiencing an unpleasant physical reaction and were confident in written information provided about allergens. All groups were less confident in verbal information provided by staff. Around a fifth of parent and child respondents and a third of adult respondents reported previously being refused service or having been asked to sign a disclaimer. It may therefore be important to investigate the ability and confidence in waiting staff in restaurants to provide suitable information for people with FH.

## **Quality of life**

All participants reported that their FH or their child's FH impacted their lives by 'quite a bit' or 'very much'. Self-reported or parental reported severity of FH was related to the level of quality of life as measured by the FH specific validated QoL scales. Severity also significantly predicted QoL for adults and teens with any FH.

FH specific QoL was also related to eating out activities in meaningful ways. Being more comfortable asking staff for information about food, and higher confidence in the verbal or written information provided about food when eating out, were related to better quality of life. However, a greater frequency with which participants had to check information at various stages of eating out was related to poorer QoL. As noted in the report for wave 1, checking behaviour may create a greater burden on the individual or parent, which has an impact on QoL. In a regression model for adults, more frequent checking of information when eating out and frequency of asking staff for information significantly predicted poorer QoL. Similarly for 8-12 year olds more frequent checking of information when eating out significantly predicted poorer QoL. For many of the parent and child models, a small proportion of variance in quality of life was explained, but few or no individual predictors were significant.

Adults, parents of children and children themselves with food allergy reported better generic quality of life than those with food intolerance or coeliac disease and those with multiple FHs often scored poorest. This was also reported in wave 1 and requires further investigation to see whether the people with different FHs require different types or level of support to help improve their QoL. For adults, reported generic quality of life was worse than UK norms. Adults with food intolerance or coeliac disease reported significantly poorer FH specific QoL in wave 1 compared to wave 2 and a further analysis of the data comparing the whole of cohort 1 and cohort 2 is required to investigate reasons for this, such as differences in clinical factors or severity for these participants. For all groups who completed the surveys at both time points, reported generic QoL

was significantly worse at wave 2 compared to wave 1. As this is generic QoL, this reduction could be due to factors beyond FH, such as the continued impact of Covid and the restrictions this has brought to day-to-day living.

In conclusion, self-reported severity, frequency of checking FH information and confidence in information about ingredients in foods were the key variables associated with quality of life. There are some limitations that should be taken into consideration:

- it is not known how representative of the UK FH population the survey is, as prevalence of different FHs are not yet known
- there is a predominance of white British adult females completing the survey (for adult and parent surveys) which is likely to have influenced the data collected
- data was collected during the Covid-19 pandemic which could have had an undue impact on day-to-day living, QoL and eating out.